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REVIEW ARTICLE

A meta-synthesis exploring caregiver experiences of home enteral tube feeding

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Abstract

Background: It is estimated that 18,232 people received home enteral tube feeding (HETF) in the UK in 2013 and HETF often requires reliance on a caregiver. Caregivers are an essential resource, and so research is needed to explore their perspectives to inform how best to support them. Therefore, this meta-synthesis aimed to explore caregiver experiences of HETF.

Methods: A systematic search and a meta-synthesis of the literature relating to caregiver experiences of HETF were undertaken. Ethical approval was obtained from Coventry University Ethics. A comprehensive search of CINAHL, MEDLINE, Academic Search Complete and SCOPUS databases was conducted, followed by a reference list search of included studies. Studies were screened for eligibility using *a priori* inclusion criteria. Included studies used qualitative methodology, were in English, and explored caregivers' experiences of supporting an adult or child receiving HETF for at least 1 month. The meta-synthesis was conducted using a thematic-synthesis method. Included studies were assessed for quality, and rigour was ensured via transparent reporting of methodology, peer review and reflexivity.

Results: In total, 328 records were screened, with 10 studies included and a total of 97 caregivers' experiences were reported. Four analytical themes were developed: loss of a normal life, psychological impact, practical challenges and becoming the 'expert'. Overall quality of the included studies was assessed as good.

Conclusions: This meta-synthesis highlighted the challenges experienced by caregivers, and revealed the need for improved HETF training for caregivers and psychological support from healthcare professionals, with the aim of providing personalised advice and regimes as part of holistic care.

KEYWORDS

home enteral feeding, feeding tube, enteral nutrition, caregiver experiences, meta-synthesis, qualitative

INTRODUCTION

The National Institute for Health and Care Excellence¹ (NICE) recommends enteral feeding for those with a

functioning and accessible gastrointestinal tract, but who are malnourished (or at risk of malnutrition) and struggling to meet their nutritional requirements orally, as a result of inadequate or unsafe intake. If long-term nutrition support

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is required, a person can be discharged home with an enteral feeding tube.²

There is scarce up-to-date information regarding numbers of people receiving home enteral tube feeding (HETF) in the UK at present. The latest British Artificial Nutrition Survey (BANS) reported that 18,232 people were receiving HETF in the UK in 2013.³ More recent data report that, in 2015, there were 3216 new HETF registrants.⁴ Data regarding children has not been updated since 2011, when 448 children were newly registered in the UK in 2010.⁵ These figures are now outdated, and the BANS has recently closed its database as a result of a decline in data submission; therefore, it is likely that the actual numbers of those receiving HETF are higher than estimated.

Guidelines state that anyone receiving HETF requires support from a multidisciplinary team (MDT); including dietitians, nurses and general practitioners.¹ The underlying conditions associated with HETF mean many patients also rely on a caregiver. The BANS⁴ report found that 59% of newly registered adults required 'some' or 'total' help, meaning that, without this support, they could either not manage to live independently or their health or wellbeing would deteriorate.⁶

Most research into HETF is quantitative, focusing on clinical issues, such as tube dislodgement, blockage and leakage, stoma site infection, over-granulation, diarrhoea, vomiting, and pneumonia.⁷ Patients receiving enteral feeding have reported the negative psychological impact that percutaneous endoscopic gastrostomy (PEG) tubes can have: impairing body image, which affects relationships, restricting freedom, and symbolising illness.⁸ As the majority of HETF recipients require caregiver input,⁴ enteral feeding is likely to also impact caregivers.

Recommendations for effective support for caregivers is highly relevant because it is estimated that caregivers provide around £119 billion of care costs per year,⁹ making them an essential resource that should be supported. Therefore, this meta-synthesis aimed to investigate the impact of HETF through the synthesis of caregiver experiences, with the aim of providing a deeper understanding of their perspectives.

METHODS

Design

A qualitative approach was utilised to provide rich insights into the lived experiences of caregivers. A meta-synthesis was considered appropriate because it allows for deep conceptual exploration of the findings of multiple studies¹⁰ to develop an understanding of the collective caregiver experience. Ethical approval for this study was granted by Coventry University Ethics (reference number P61614).

Searches and study selection

Eligibility criteria were defined *a priori* and included studies were qualitative, English language and provided an

exploration of caregivers' experiences of HETF an adult or child for at least 1 month. For the purpose of this study, a 'caregiver' was defined as a layperson who 'provides unpaid support to a partner, child, relative or friend' who is reliant on their help with HETF.⁶

Data were collected online via a systematic search of the literature. The search strategy was informed by the PICO framework, adapted for qualitative use: (P) population (caregivers), phenomenon of (I) interest (HETF) and (CO) context (experiences) (see Supporting information, Table S1). Searches were initially conducted by the lead researcher (SS) during February 2018, then updated using the same search strategy in January 2020 (see Supporting information, Table S2 and S3). CINAHL, MEDLINE, Academic Search Complete and SCOPUS were searched because these databases are relevant for healthcare research. Reference lists of included studies were searched to identify any additional relevant studies. A summary of the study selection process is presented in a Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) Flow Diagram,¹¹ Figure 1.

The literature from the searches was assessed by the lead researcher against eligibility criteria. Studies including both quantitative and qualitative data, or experiences of caregivers along with patients or HCPs were only included if findings could be clearly differentiated.

All included studies were appraised using the Critical Appraisal Skills Programme¹² (CASP) checklist for qualitative research, allowing discussion of the strengths and weaknesses of the body of evidence.¹³ Quality was not used as a threshold for inclusion because lower quality studies can still provide new insights.¹⁴

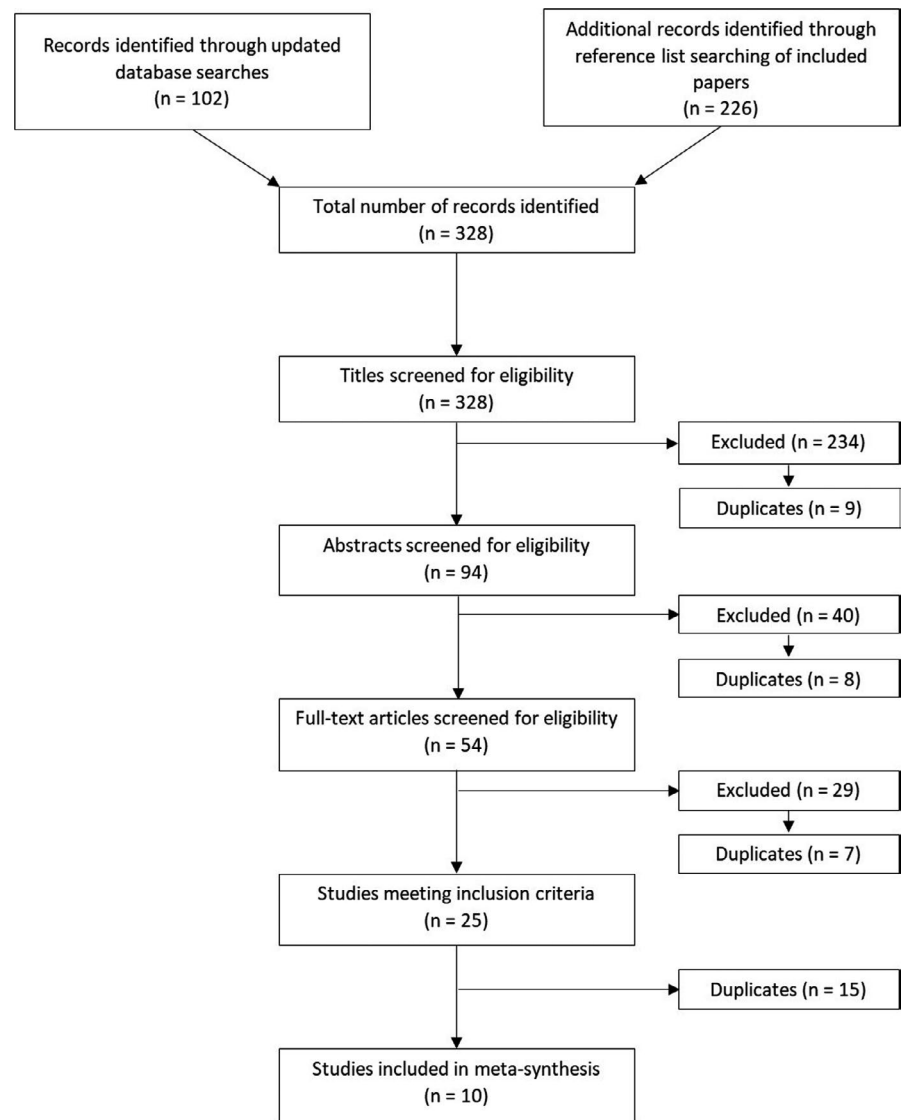
Data extraction and synthesis

A study summary sheet and data extraction tool were created and piloted by the lead researcher in accordance with the PRISMA checklist,¹¹ using one qualitative study.¹⁵ The data extraction tool was adapted, based on feedback from the second researcher (BT). Data from the included studies were then extracted by the lead researcher.

The meta-synthesis was based on the results of the six originally included studies via an iterative process. It was conducted by the lead researcher using the 'thematic-synthesis' method, specifically created for qualitative systematic reviews.¹⁶ This involved three stages: line-by-line coding of the results of primary studies, organising the 'free codes' by developing 'descriptive themes' and then generating 'analytical themes'.

Line-by-line coding of results from included studies produced 289 meaningful free codes. Across the included studies, 53 descriptive categories were created, then combined and grouped into 12 descriptive themes. Throughout this process, the categories and themes were re-assessed, re-organised and refined by the lead researcher. Peer review with the second researcher reduced the descriptive themes to 10, which were discussed further to synthesise four analytical themes (see Supporting information, Figure S1).

FIGURE 1 Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow diagram



When the searches were updated in 2020, the four new included studies were felt to fit with the existing themes, and so were incorporated into these as appropriate. These were peer-reviewed by the second researcher.

RESULTS

Study characteristics and sample demographics

In total, the experiences of 97 caregivers were reported. A table summarising the study characteristics and sample demographics of the 10 included studies is shown in Table 1.

Statement of quality

Appraisal of the included studies with the CASP checklist¹² revealed the overall quality of the body of evidence to be

good, and the results are considered to be credible. A summary table is provided in the Supporting Information (Table S4).

Overarching themes

Four analytical themes were synthesised: loss of a normal life, psychological impact, practical challenges and becoming the 'expert' (Figure 2). The terms 'parent caregiver' and 'adult caregiver' are used to distinguish between mothers and fathers caring for children (parent caregivers), and spouses, partners, sons and daughters caring for adults (adult caregivers). Each theme and subtheme is described below.

Loss of a normal life

The experience of losing a normal life was a prominent issue for many caregivers, particularly parents.

TABLE 1 Study characteristics and sample demographics

Year	Authors	Country	Method of data collection	Number of caregivers	Age of caregivers	Relationship to patient
1997	Thorne, Radford & McCormick ¹⁷	Canada	Interviews	7	Unspecified	4 foster parents 3 biological parents
1998	Spalding & McKeever ¹⁸	Canada	Face-to-face interviews	12	30–49 years	Mothers
2003	Liley & Manthorpe ¹⁹	UK	Face-to-face interviews	5	Unspecified	Family members/spouse
2005	Sleigh ²¹	UK	Face-to-face interviews	6	Unspecified	Mothers
2006	Brotherton, Abbott & Aggett ²³	UK	Face-to-face interviews	19	Unspecified	5 wives, 7 husbands, 1 partner, 3 mothers, 1 daughter, 2 sons
2007	Brotherton, Abbott & Aggett ²⁰	UK	Face-to-face interviews	24	Unspecified	21 mothers, 3 fathers
2011	Mayre-Chilton, Talwar & Goff ²⁵	UK	Focus groups	3	40–70 years	2 partners, 1 child
2018	Russell, Jewell, Poskey et al. ²⁴	US	Telephone interviews	6	Unspecified	5 mothers, 1 father
2019	Ang, Lim, Ng et al. ²²	Singapore	Face-to-face interviews	9	44–74 years	Family members
2019	Phillips ²⁶	UK	Face-to-face interviews	6	Unspecified	Mothers

Abbreviations: NGT, nasogastric tube; PEG, percutaneous endoscopic gastrostomy.

Stigma

Perceived stigma was one reason for HETF leading to loss of a normal life. Some came from professionals, as several parents experienced:

... overt disapproval from ... teachers and psychologists, who perceived the gastrostomy as an impediment to mainstreaming the child¹⁷

Another aspect of stigma was the abnormality of the gastrostomy itself; several parents described it as a 'hole' in their child, and there was repeated use of the words 'unnatural' and 'abnormal' throughout the parents' accounts. One mother's particularly vehement description revealed the intense stigma she felt was attached to her child's gastrostomy and the impact this had, as her understanding of what was 'normal' had to shift:

[The gastrostomy tube] ... was the most horrific, outdated, terrible thing to put in a child. It was an awful looking thing and most awful thing to deal with that we ever, ever experienced

in our lives. It changed our lives. It had such an impact, it was so permanent for her, it was a hole in her, it was like this gaping hole in her abdomen. I mean, the way I had to touch her, treat her and position her changed. Everything changed for us ...¹⁸

One adult caregiver mentioned the stigma of enteral tube feeding, and her husband's embarrassment of his gastrostomy, resulted in isolation from her normal life:

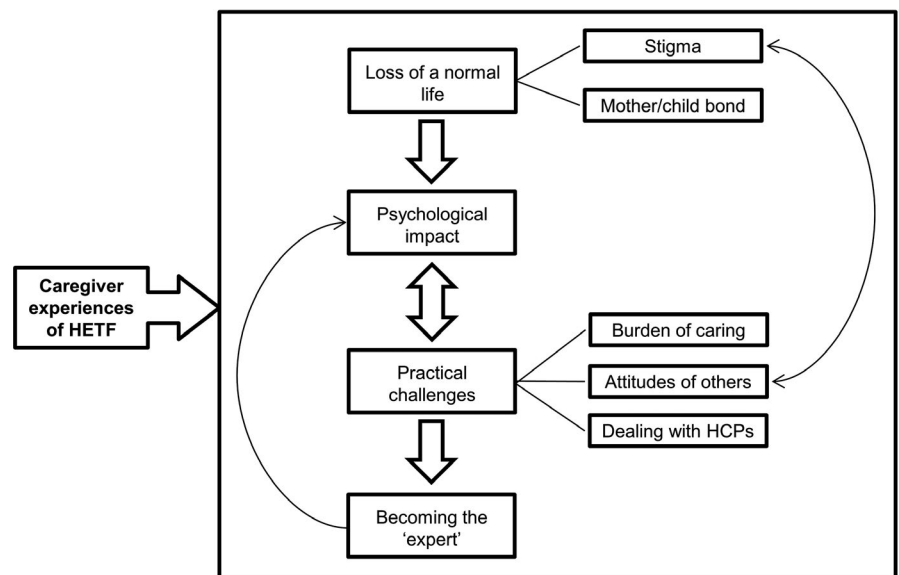
He doesn't want anyone to know and so we can't go out [for a meal]. He even gets bad tempered if I want anyone around, he can't find a reason for not eating in front of them, not even a cup of tea. We always used to be out ...¹⁹

Mother/child bond

Caregiving mothers demonstrated a specific loss of normal life. There was overwhelming consensus that feeding one's child was intrinsic to mothering, and its loss engendered

Time HETF	Reason for HETF	Age of patient	Type of enteral tube
Several years (specific timeframe unspecified)	Children with disabilities (specific diagnoses unspecified)	Unspecified	Gastrostomy
1.5–8.5 years	9 congenital chronic illnesses, 3 severe acquired brain injuries	3–12 years	Gastrostomy
≥12 weeks	Neurological damage, stroke, underweight from respiratory disease	45–84 years	PEG
6 months - 3 years	Cerebral palsy	2–16 years	4 PEG, 2 gastrostomy with fundoplication
2 months - 9 years and 4 months	Oesophageal cancer, multiple sclerosis, motor neurone disease, cerebrovascular accident, cerebral palsy	20–84 years	PEG
2 months - 7 years and 8 months	3 cystic fibrosis, 2 failure to thrive, 3 schizencephaly, 6 global developmental delay, 4 cerebral palsy, 6 other rare conditions	1 year and 10 months - 14 years and 8 months	PEG
Minimum of 3 months	Head and neck cancer	Unspecified	Gastrostomy
At least 1 month	Cerebral palsy	1–28 years	Gastrostomy
'Long-term'	5 malignancy, 1 functional decline, 2 Parkinson's disease, 1 stroke-related	Unspecified	6 PEG, 3 NGT
< 1 year - > 5 years (using blended diet)	Unspecified	6–31 years	Button gastrostomy

FIGURE 2 Concept map. HCP, healthcare professional; HETF, home enteral tube feeding



feelings of maternal failure. Many mothers missed the closeness that came with feeding their child, stating enteral feeding lacked the emotion of nurturing:

I think you do lose that closeness with your child because there is no physical contact, it is not a pleasant experience ...²⁰

Several parents left their child alone when they were pump feeding, which further disrupted bonding:

When she is on the pump having a feed it's all too easy to go off and do, and get something done²¹

Psychological impact

Across the included studies emerged a sense of caregivers' mixed feelings. Despite mourning the loss of a normal life, once caregivers saw the benefits of tube feeding, they felt a sense of acceptance:

... it is a necessary evil that has to be done²⁰

We just ... we usually internalise it as part of the process and we just accept it²²

However, for some parents, seeing the physical improvements in their children produced guilt, as they regretted not taking this action earlier:

... I look back in retrospect, it should have been done far earlier ... So then I feel guilty because I didn't push harder at the time ...¹⁷

Caregivers also experienced feelings of guilt when eating in front of their loved one who could not participate, and this altered their behaviours and enjoyment of food:

I only cook dishes that I know he didn't like. I couldn't sit and eat his favourite meal while he cannot even have one mouthful²³

Practical challenges

The general consensus from caregivers was that HETF had benefits and was essential for their loved one, though they acknowledged this involved difficulties. Caregiver experiences of dealing with the practical challenges of HETF were revealed and, unfortunately, most reports were negative.

The burden of caring

The main practical challenge faced by caregivers was adapting to the routine and equipment involved with HETF, making HETF feel burdensome. Several caregivers commented on the volume of equipment that arrived at their houses:

I had no idea how much stuff would be arriving and it was all left on my kitchen floor ...¹⁹

Many caregivers reported difficulties integrating HETF into their daily lives, finding it time consuming and inhibitive:

... If we are eating out to dinner somewhere, we have to make sure we have food for later, so that she is not missing a meal. So it ends up being a lot of planning²⁴

Caregivers described their experience of sleep disturbance from overnight feeds and resulting family conflict because of tiredness. Parent caregivers likened this disruption to caring for a newborn baby:

In the middle of the night we are saying to each other 'it's your turn to feed her'; 'no it's your turn', like you do with new born babies, it's like being stuck in a time warp at that feeding stage²⁰

Dealing with the practicalities of HETF left many caregivers feeling they were providing 24-hour care for their loved one. Caregivers took full responsibility and struggled to come to terms with the social isolation they experienced due to demanding feed regimes, creating feelings of resentment:

We don't have a social life. I did earlier on ... but my normal social life stopped existing 14 months ago. I had lots of interests that have all stopped. I miss them an awful lot²³

This not only impacted on caregivers' time for themselves, but also on family time due to restrictions of the feed regime:

It is not good for the family, I don't think other people really understand ... we have to plan and then two of us would stay at home whilst the other two go. It is splitting the family²⁰

Parent caregivers reported abandoning family holidays as the feeding organisation was prohibitive; other families had tried going away and regretted it as a result of the burden of feeding:

We would love to go abroad on holiday, and my other child would love to go, but because of her situation [feeding every four hours], we aren't risk it so that stops a holiday abroad²⁰

Conversely, several parents reported a more positive experience, stating:

Wherever we go, he comes. And we just make sure we've got his chair and his feeding pole and his pump and his food, and it's just, instead of packing for a baby, you're packing for him ... you

just get used to it. It's just a part of something that you do. Yeah, it's called life¹⁷

Attitudes of others

The attitudes of others exacerbated the practical challenges of HETF. There were many accounts of caregivers providing enteral feeds in public and experiencing negative reactions:

I have asked the manager if it is ok to feed her and he has made me go and sit in the disabled toilet and feed her in there ...²⁰

This deterred caregivers from feeding in public, which further limited the caregivers' social interaction as the feed regime was restricted to the home:

I always make sure I feed her before we go out. I wouldn't feed her outside again²⁰

Negative attitudes of family members added to the practical challenges of HETF. Extended family were unwilling or nervous to be involved with the child, placing greater strain on the caregivers:

My mother-in-law has a problem with him; she finds it difficult. She walks out of the room, I have offered to show her how to feed him but she has declined²⁰

Dealing with healthcare professionals (HCPs)

Dealing with HCPs was another practical challenge experienced by caregivers. Some of this was negative because caregivers felt that HCPs had taken control of their lives. Caregivers reported feeling confused by HCPs because they received mixed messages. It seemed ridiculous to caregivers following years of variable intake pre-gastrostomy that dietitians were obsessed over the daily feed intakes.¹⁷ Other caregivers reported receiving conflicting advice:

I think all you professionals have learned in different places and when you are all saying different things I don't know who I am supposed to listen to²³

Although HETF training included demonstrations of techniques by HCPs, it 'did not always extend to support in integrating the process of HETF into other household routines and spaces'.¹⁹ It was also suggested that a psychological aspect was missing from the training:

Very important for the carer is to understand the psychology ... sometimes carers feel totally isolated²⁵

Becoming the 'expert'

Despite these challenges, caregivers worked relentlessly to overcome difficulties and make HETF work because it was essential for their loved ones' survival. As their confidence increased, caregivers described how they became skilled at HETF, regarding themselves as the 'experts'. Caregivers wanted recognition for their skills and vital role, and lost confidence in HCPs if they sensed inexperience, which further promoted caregivers' self-reliance. Many, particularly parents, adapted prescribed feed regimes to suit their lifestyles and routines after finding the professional's recommendations unrealistic:

You just have to work with your experience on your own child ... You have to experiment, and respect yourself, because each child is different.¹⁷

Many parents questioned the nutritional value of the feed, with one caregiver describing prescription feeds as 'chemical milkshake'.²⁶ This led to many caregivers going against recommendations at the time and putting liquidised home-cooked food through the gastrostomy tube, now known as a 'blended diet':

It just seems healthier and it just feels like a more natural way for [name] to ... have her food²⁶

Many caregivers (particularly parents) believed HCPs should provide more support and guidance for blended diets and wanted it offered as an alternative. This desire partnered with lack of advice and support from HCPs often led to caregivers working it out for themselves or consulting the internet. Many also believed HCPs should devise means to reinstate oral feeding because they wanted the tube to be temporary. Some tried starting oral feeding by themselves, without professional support:

We offer him whatever we are eating ... if there's something that's hard ... he can't chew it, I will chew it for him and give it to him in his mouth so he can taste it, and experience it, and smell it ... We have never deprived him¹⁷

Caregivers reflected that to achieve the normal life they desired they needed to become skilled in HETF and integrate it into daily living, creating a new normal.

... A lot of it though, was just finally recognising that this is her normal and this is the normal for our family²⁴.

DISCUSSION

This meta-synthesis is the first to investigate caregiver experiences of HETF, exploring this perspective to inform the

MDT and improve holistic practice. The results have revealed rich descriptions of experiences, showing the journey and challenges of becoming caregivers.

Overall, the caregiver experience of HETF revealed a process of mixed emotions. For many, there was initially a period of distress, facing the loss of their normal lifestyle and the stigma attached to enteral feeding. For mothers, this had a profound impact because they missed the closeness associated with breast or bottle feeding. These losses had a psychological impact on caregivers; however, this developed to acceptance as they came to acknowledge that their loved ones' survival depended on it. Sometimes, a sense of guilt emerged regarding whether a tube should have been placed sooner or their enjoyment of food isolating their loved one. Caregivers acknowledged that, although HETF was essential, it involved many practical challenges they had not expected, including the burden of caring, the impact of attitudes of others (influenced by stigma), and dealing with HCPs. The relationship between psychological impact and practical challenges was two-way because the psychological state influenced the ability to cope with challenges, and challenges impacted the psychological state. Caregivers put great effort into overcoming challenges, eventually becoming confident with HETF, even taking feed regimes into their own hands. Eventually many defined a new normal, which influenced their psychological state and aided acceptance.

One of the most striking caregiver experiences in the present study was that HETF was a burden because prescribed feed regimes did not fit into caregivers' lifestyles and were unrealistic to manage. Caregivers reported feeling unprepared for dealing with the practicalities of HETF. A UK study by Brotherton and Abbott²⁷ interviewed patients and caregivers dealing with PEG tubes and identified that only 37% felt the information provided during PEG training was useful and 33% felt it was sufficient. Patients and caregivers reported that training provided information on the feeding pump itself but left unanswered questions about the practicalities of HETF, which was what they really wanted to know, reflecting the caregiver experiences revealed in this meta-synthesis.

A 2019 meta-synthesis by Thomas *et al.*,²⁸ exploring the impact of HETF on the daily lives of patients with head and neck cancer, reveals similar themes to those in the present study. Mourning the loss of one's previous life and the difficulties adjusting to a life now defined by HETF appear to be challenges faced by both patients and caregivers. The present study and this meta-synthesis²⁸ have both described the experience of HETF as a 'journey' and the importance of creating and accepting 'a new normal' to manage the changes.

Caregivers in this meta-synthesis reported experiencing a significant emotional journey and psychological impact. NICE¹ guidance states that HCPs should ensure caregivers are able to discuss social and psychological needs; however this meta-synthesis has raised questions regarding whether psychological support is available. It is crucial for HCPs to ask about caregiver experiences in HETF consultations and

follow this with appropriate support, to prevent caregiver burnout. New ESPEN guidelines²⁹ now acknowledge the impact of HETF and need for support, recommending that quality of life of both the patient and caregiver should be measured periodically to minimise the impact of HETF on daily life.

Strengths and limitations

A strength of this meta-synthesis is that it breaks new ground exploring caregiver experiences of HETF. Reflexivity (see Supporting information, Table S5) and risk of researcher bias were considered throughout, and the use of a validated method to conduct the meta-synthesis and transparent reporting reduces the influence of the researchers. The data summary sheet and extraction tool were piloted, following PRISMA¹¹ best practice. These tools helped to ensure consistent recording of relevant information and maintained researcher objectivity. A range of databases were searched, along with reference list searching, as per Centre for Reviews and Dissemination¹³ guidance, ensuring a comprehensive search. However, unpublished studies and non-English language studies were excluded, posing the risk of both publication and language bias.

Because this was secondary research, the quality of the included studies affects the quality of the synthesis.¹⁰ As illustrated by the summary table (see Supporting information, Table S4), the two oldest studies^{17,18} have the poorest quality. A possible explanation could be changes in the standards of reporting since the 1990s. It is also important to acknowledge the developments in HETF provision that have occurred since this time, such as improved pump technology and the availability of specialist products. However, lower quality and older studies were not excluded because their results reflected the higher quality and more recent studies, suggesting that they still provide valuable insights into the caregiver experience.

To ensure the themes conveyed the collective experience and reduce risk of reporting bias, quotes from all 10 included studies were incorporated to illustrate the themes. Six of the 10 included studies were conducted in the UK, meaning that the results are valuable for challenging and informing UK practice.

Although there are likely to be different experiences between parent and adult caregivers, there is currently a lack of evidence on this topic because only 10 of the 289 records identified met eligibility criteria for this meta-synthesis. Therefore, a focus on only one caregiver group would not have produced sufficient data to form a rich and in-depth understanding of the topic. Experiences of caregivers could also vary depending on the underlying reason for the patient receiving HETF (e.g., stroke, cerebral palsy, motor neurone disease, etc.) because different conditions require varying levels of caregiver input. Although this could influence caregiver perceptions of the HETF experience, currently, there are insufficient numbers of primary studies focusing on one specific underlying condition to be able to synthesise data in this way.

CONCLUSIONS

This research has achieved its aim because it has revealed new insights into caregiver experiences of HETF, demonstrating an emotional process of learning as caregivers strived to overcome challenges and create a new normal.

Implications for practice

This research identifies that current training may insufficiently prepare caregivers for managing the practicalities of HETF. If training included information on logistics, alongside planning how the feed regime could be integrated into normal life, caregivers should feel better prepared. Creation of a 'best practice' standardised training programme could be useful for facilitating high-quality training across different hospital trusts, aiming to ensure that training is fit for purpose and meets the needs of caregivers, as well as patients. This recommendation for standardisation of training is now also reflected in the new ESPEN guidelines²⁹ aiming to improve quality of HETF care.

If health professionals could offer group sessions as training updates for caregivers, this may reduce their experience of mixed messages, check safe practice and promote peer support to aid mental wellbeing. Extending this training to include extended family members and friends could help to alleviate caregiver burden and reduce stigma.

This meta-synthesis also highlighted caregiver interest in blended diets; therefore, dietitians need to be prepared to discuss this and provide evidence-based advice. The British Dietetic Association produced a policy statement³⁰ for this in 2019 and now suggest blended diets as an option where there are potential physiological, social or emotional benefits to the patient and their family, recognising the needs of caregivers alongside the needs of patients.

The guilt felt by caregivers when unable to share food with their loved one was also revealed, and it was identified that oral feeding may be taking place against recommendations because of this. Greater MDT focus on reinstating some aspect of oral feeding, even if only tastes of certain 'safe' foods, could help reduce unsafe practice from caregivers and alleviate any feelings of guilt around the enjoyment of food.

HCPs also need to affirm the role of caregivers, acknowledging their experience by seeking input during assessments and discussing their social and psychological needs to prevent caregiver burnout.

Recommendations for future research

New research into this topic could compare the experiences of different caregivers based on their relationship to the patient or the underlying condition requiring HETF, aiming to determine whether this affects the experiences and needs of caregivers. Future qualitative studies into this topic need

to ensure transparent reporting to facilitate a high-quality body of evidence.

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with PRISMA guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

ACKNOWLEDGMENTS

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CONFLICT OF INTERESTS

The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS

SS and BT were involved with study design, screening against eligibility criteria, interpretation of results and study write-up. Database searching, data extraction and data analysis were completed by SS as lead researcher.

ETHICAL APPROVAL

Ethical approval was granted by Coventry University Ethics.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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